



LYMPHEDEMA
ASSOCIATION OF
ONTARIO

2020 E-VOLUME 3



Message from the President

Dolores Steinwall | August 06, 2020

Dear Members,

I hope this newsletter finds all of you in good health and enjoying the sunshine. Thank you for sharing your inspiring stories, [and please continue to send them to us.](#) We are publishing three in this newsletter.

We are launching a **Virtual Fundraiser, CHALLENGE: LYMPHEDEMA for the month of September.** The funds raised will go to:

1. Launching a 3 month pilot of the Compassion Fund, which I spoke about at the AGM. The intention of this fund is to provide and teach MLD treatment for patients that need financial assistance. The pilot period is scheduled to run from September 1st to November 30th

2. Continuing to provide Webinars to educate and raise awareness to the LE community
3. Info-line administration. Popular demand of the hotline means we need to track and analyze the data to create a business case to present to the Ministry of Health to advocate on behalf of patients for additional resources and government support
4. Organizing a virtual support group for patients. We are welcoming therapists, as well as any providers who support those in the Lymphedema community, to let us know if they are able to volunteer in this program

Our administration costs are less than 10% of money raised!

Here are the details of the Virtual Fundraiser:

CHALLENGE: LYMPHEDEMA

DATES: September 14th to October 13th

DONATIONS: LAO website or Canada Helps. Donations over \$25.00 will receive tax receipts

LOCATIONS: All Virtual! Which means that wherever you are, you can participate – we have team leads representing the following areas that anyone can join: Windsor/LaSalle, Chatham, Ottawa, Peterborough, Toronto, Pickering, Burlington, Markham and Simcoe. This is your invitation to become a team leader, or member of a team, in your online community now!

WHO: Members and their friends and families (their bubble of 1-10 or more if done virtually)

WHAT: Walk, run, cycle, yoga, meditate, dance, Nordic pole walk, hike, swim or simply any activity that you like to do!

The choice is yours; simply make the commitment for 30 days. E.g. walk for 15 mins everyday or meditate 5 times per week. For further details please email [Janet](#).

There will be webinars, posts and more to support and showcase all of our participants' efforts to raise awareness and funds!

Please email volunteer@lymphontario.ca to get set up with Canada helps.

Stay tuned for more announcements and information during the next few weeks posted on our website Lymphontario and social media.

[Join the CHALLENGE: LYMPHEDEMA!](#)

AGM Highlights – June 11, 2020

[Click here to read document in full on our site](#)



Tony Wight

Board Director, Awareness & Secretary

The Annual General Meeting for Fiscal Year ending March 31, 2020 was held virtually by Zoom on June 11, 2020. The following are highlights:

Introductions of Current Board of Directors - Dolores Steinwall, Rob Caparelli, Tony Wight and Charlotte Schultz.

Support Staff - Sara Waddell (Administrator) Rachelle Macdonald (Bookkeeper)

New Advisory Committee Members - Ann DiMenna, Sophia White, Jaclyn Jones, Janet Vanderveen and Tony Schultz

Approval of Resolutions - by electronic ballot in advance of meeting - (numbers 5, 6 and 7 were passed by the Board of Directors and approved by Members- copies scheduled to official Minutes):

1. Acceptance of Agenda for LAO Annual General Meeting June 11th, 2020
2. Approval of Previous LAO 2019 AGM Minutes
3. Appointment of Melissa Coulson as Chartered Professional Accountant for LAO YE 2020 Statements Approval
4. Approval of LAO YE 2020 Financial Statements
5. Name Change - as per Schedule 1*
6. By-Law Revision - Board Member Qualifications – as Per Schedule 2*
7. By-Law Revision - Members meetings Quorum – as Per Schedule 3*

(*available on AGM webpage)

Significant accomplishments during past fiscal year report by President (Dolores Steinwall)

- “Six Things a Patient Should Know About Lymphedema” card published
- E-Newsletter launched
- 4 successful fundraising events held
- Provincial Association Committee (PAC) established

Goals for current year:

- add Medical Advisory Committee
- review Compassion Fund with small task force of therapists for feedback prior to activating
- form small task force to launch support group for patients
- organize fund raising events including virtual runs and walks in different locations

LAO Founding Members recognized -

Cathy Cotton, Glen and Margaret Gagan, Ruby Kreindler, Pamela Hilliard and Kim Gagan

Member Stories

We are launching our Members Stories, anecdotes from our community of those with Lymphedema, and those that help us treat and manage it.

Diane Lieder, Chatham-Kent Ontario:

I have had Lymphedema since my first pregnancy when I gained 58 lbs, in 1974. My legs were so swollen, I could only get sandals on. It appeared to improve afterwards until my second pregnancy. I had the same issues and was put on a fluid pill. Afterwards it seemed to improve again until a few years later. My legs were always extremely swollen and painful. In 1983, I had to quit full time work and went part time call in. No one knew the reason this was occurring. I saw many Doctors with absolutely no help. I gained 85 lbs in a short time. One Doctor in London, said I don't know why it should upset you, gaining 14 lbs in a few hours. He then said we don't do research on that because only women get it.

In 2016, I saw a vascular surgeon for ugly blue veins in my ankle. He sent me for several tests and finally a Lymphoscintigram. The first between the toe injections didn't work so he had to repeat. My doctor nor I weren't sure what wasn't working. I was diagnosed in 2016 at which time I travelled to London to be taught Manual Lymph drainage still not fully knowing why. I found out through a letter in the mail that I had Lymphedema and that I was now on my own to deal with it.

I found Facebook groups about Lymphedema where I learned that I should see a Lymphedema therapist. I was fortunate to find one who is passionate about Lymphedema, Maddie Simone. I did one fundraiser with a friend for the LAO and we have done 3 Lymphedema walks in LaSalle.

Because I wanted others who were diagnosed to not feel alone after being diagnosed, I started the Lymphedema Awareness Network, Chatham-Kent.

Jane Mical, Toronto:

In 2010, my Mom was diagnosed with cancer. While staying at the hospital with her, the Oncologist and I started talking about massage and cancer (I was studying to be a Registered Massage Therapist). The Oncologist was very supportive of massage during cancer treatments, and gave me some studies that supported oncology massage. She also mentioned MLD, as my Mom had whole-body swelling due to steroids. That was the first I'd heard of lymphatic drainage, so I looked it up, liked what I read, and was horrified to learn how misunderstood and misdiagnosed lymphedema was, and how common it was to develop it after cancer treatments (especially after a lymphadenectomy and/or mastectomy). Considering how much rudimentary massage & lymphatic drainage helped my Mom, I decided that I wanted to make MLD-CDT and cancer rehab my clinical focus. So I did. I learned MLD-CDT at the Vodder School International, took additional courses in traumatic scar tissue management, and am now working at a clinic that focuses on all types of lymphedema.

Cheers, Jane Mical, RMT, MLD-CLT LANA

Leda Raptis, Kingston, as written by her friend and peer:

Her lymphedema diagnosis caused by previous breast cancer surgeries didn't stop her from a path to help others! Leda Raptis, a professor in the Department of Biomedical and Molecular Sciences at Queen's University in Kingston, Ontario was concerned about the lack of protective equipment in the ICUs during this COVID pandemic. "My God, the need is huge, how can they work with patients coughing nasty virus around without enough masks?"

So, she sat down at her sewing machine and got to work making masks for the healthcare professionals that needed them to help others still.

In 2010, Raptis was diagnosed with breast cancer and went through the treatments including surgery, nodal dissection, chemotherapy and hormonal therapy. Soon after, she developed lymphedema, and compression started. She had to make several modifications to her class 2 compression sleeve and gloves (e.g. bringing the thumb to a natural position and adding a small cushion in the inside of the glove) to adjust them perfectly to her arm anatomy. Several infections (cellulitis) to her arm made the lymphedema challenging to control. However, a visit with Dr. Towers helped enormously in reducing the incidence of infections and managing her lymphedema! She learnt that in her case, the trick was using less compression (class 1), not more! This is why consulting with specialists is important; to evaluate the individual needs of each patient in an effort to optimize their lymphedema management.

So, with her lymphedema under control and a skill set that's much needed during this pandemic, she got out her sewing machine and got to work. With the help of her husband, Kevin Firth cutting the material, it takes Raptis about three minutes to sew each mask, to the tune of up to 50 a day. She made over 300 masks for hospital people, till shipments came and they were not needed any more. All that with a well-fitting, compression glove and sleeve on!

Later, as the labs at the university were starting to re-open, her colleagues asked for masks for their students. They wanted to pay her for them, but instead she told them to make a donation to Breast Cancer Action Kingston, and later to the Ontario Health Coalition. Then in June the horrific murder of George Floyd happened and the donations went to Black Lives Matter, in the name of those affected by this matter including her dear students and colleagues. She has made over 780 masks total so far, with 160 ready to go, plus several more for kids.

Raptis is not alone in her enterprise. Once community members heard about her kind efforts, elastics were donated to her, at the time when there was no elastic anywhere in sight! She feels so blessed for the help of Dr. Towers and her team who made it possible to manage her lymphedema and in turn be able to give back to her community by helping others during this COVID pandemic.

A big thank you to the members who have shared with us and we look forward to other members submissions.

Please send any submissions to [Admin](#).

We ask that all submissions be of a personal tone and under 250 words.



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